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**The National Bowel Cancer Screening
Programme in Cheshire and Merseyside:
perspectives of people with a sensory
impairment**

Executive Summary

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Executive Summary

Background to the research

Bowel cancer is the third most common cancer in the United Kingdom but early detection through regular bowel cancer screening can reduce the risk of dying by 16%. The National Bowel Cancer Screening Programme was introduced in England in 2006, offering screening to all adults between the ages of 60 and 69 years every two years, with a planned extension to the 70–75 year age group in 2010. The Cheshire and Merseyside Bowel Cancer Screening Programme, which is part of the North West Strategic Health Authority, commenced in September 2006.

This research project was initiated by the National Bowel Cancer Screening Programme, which was interested in exploring the accessibility of the programme for people with a sensory impairment as part of their strategy for addressing inequalities in health. The accessibility of the screening programme is a key issue because the success of the programme in the early detection of bowel cancer is, in part, dependent on the uptake of the initial invitation to participate. Enabling people in the target audience to participate is therefore of primary concern. However, research to date suggests that for people with a sensory impairment, there may be considerable barriers to their active participation in bowel cancer screening, particularly in relation to completion of the faecal occult blood test. Given that hearing and sight problems are more common in those aged 60 and over – the target audience for bowel cancer screening – this is a matter of particular concern.

The aim of the research was to explore the experiences, perceptions and understandings of people with a sensory impairment of the first stage of the screening process, from invitation to participate, to completion of a faecal occult blood test. The specific objectives of the study were to:

- explore how research participants understood and would negotiate the first stages of the bowel cancer screening process;
- identify any actual or perceived difficulties with the process;
- identify the coping strategies they used or would use to help them participate in the process.

Methodology

This was a qualitative study which made use of focus groups and interviews. Participants were recruited through voluntary organisations in Cheshire and

Merseyside. All data collection sessions were recorded and subsequently transcribed verbatim. A thematic analysis was carried out in order to identify recurring themes and sub-themes.

Key findings and conclusions

People's knowledge, understandings and perceptions of the screening process and the specific steps involved, including the consequences of testing, are likely to be important influences on their decisions to participate. However, there are also a number of additional considerations with the faecal occult blood test that can threaten participation, even when people are well-motivated and have the best of intentions. The evidence from this study suggests that – for older people in general and for sensory impaired people in particular – participating in the screening process by completing the test kit was not always simple, straightforward or acceptable.

Many of the comments made by participants in this study related to practical changes to make their participation easier as well as strategies that could be used to motivate people with a sensory impairment to overcome the effort participation can require. In this respect, the recommendations presented here are likely to benefit many participants in the programme, not solely those with a sensory impairment.

Recommendations relating to increasing knowledge

- Directly engage with support organisations for sensory impaired people in order to ensure wider dissemination of information about the screening programme.
- Consider training ambassadors for the screening programme within the deaf community to disseminate the programme's message and instructions on how to participate.

Recommendations relating to strengthening sources of help

- Screening programme staff need to work closely with healthcare staff, social services and the voluntary sector to support sensory impaired people.
- Screening programme staff need to target support to residential homes and work closely with staff to ensure that these people are not overlooked.
- A textphone and e-mail helpline need to be established.
- Target individuals who may be more isolated through outreach work to promote the screening programme and ensure that all individuals have access to personal support if it is required.

Recommendations relating to improving written information

- Language used in written materials should be simplified and the amount of text in written materials should be reduced to improve readability.
- Complex medical terminology should be avoided if possible.
- Include more pictorial and diagrammatic information on written materials.
- Give consideration to the creation of information DVDs with different communication options, for example, subtitles in straightforward language or an interpreter.
- RNIB readability guidelines should be used to format the text used on written documents, such as left aligning the text, to improve the readability for people with a visual impairment.
- A clear, large NHS logo should be included on written materials to alert readers to the significance of the letter.
- Consultation with equipment specialists would ensure that written documents are compatible with screening equipment.
- Large print, audio and Braille copies of all written materials should be made available to all people on request.
- An explicit statement highlighting the availability of alternative formats should be positioned at the top of all written materials in large, clear font.
- Consider identification of patients with a sensory impairment through GP records prior to dispensing written invitation to the programme.
- Contact people who do not respond to postal invitation by alternative means.

Recommendations relating to improving the design of the kit

- Consideration needs to be given to making a larger kit with windows positioned further apart from one another.
- Consider the production of separate kits for each sample to avoid the contamination of separate samples.
- Provide a larger area in which patients can record the date of their sample.
- Explore the use of sending larger sample pots through the post with Royal Mail.
- Produce larger labels for patients who use alternative sample pots.